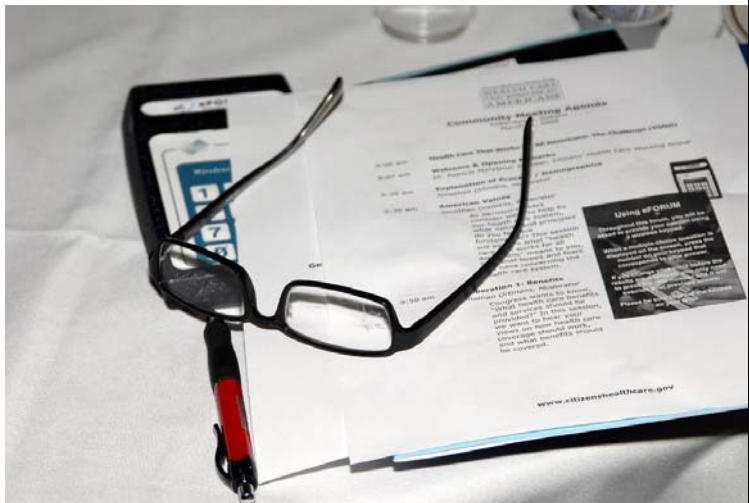
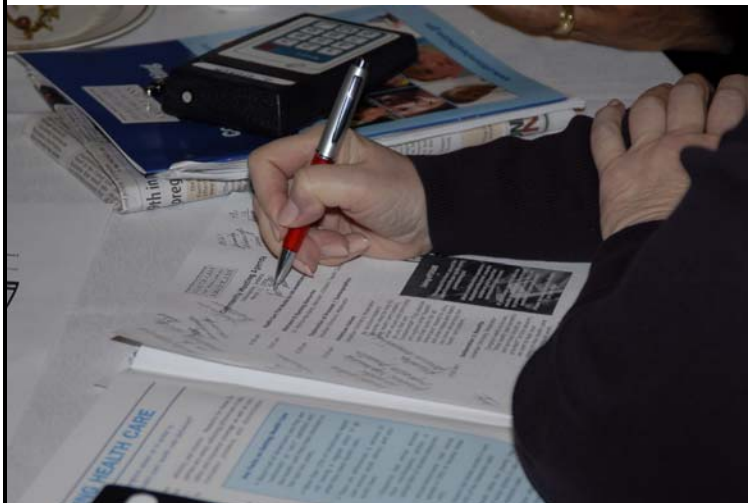




Upper Valley

March 31, 2006



Citizens' Health Care Working Group

HEALTH CARE
THAT WORKS FOR ALL
AMERICANS

OVERVIEW

After a New England winter, nothing is more life-affirming than the first days of spring. In the Upper Connecticut Valley of New Hampshire, winter was officially over on March 31, a stunningly beautiful day. Thus, it was especially impressive that over 100 people chose to be indoors in Alumni Hall of Dartmouth College on a late Friday afternoon to discuss "Living Well Through the End of Life" and what this means for "Health Care that Works for All Americans."

Dr. Ira Byock, Director of Palliative Medicine, Dartmouth-Hitchcock Medical Center, facilitated the meeting. He began the meeting with a presentation on key factors to keep in mind as the group considered "last days," including how competitiveness is stifled by high health care costs, administrative costs of the system, large numbers of personal bankruptcies because of health care costs and the system's complexity. He also noted the public's failure to deal with end of life concerns, in part because of cultural avoidance, and how the limited response tends to focus exclusively on medical issues.



Citizens' Health Care Working Group Community Meetings

Kansas City, Missouri
Orlando, Florida
Baton Rouge, Louisiana
Memphis, Tennessee
Charlotte, North Carolina
Jackson, Mississippi
Seattle, Washington
Denver, Colorado
Los Angeles, California
Providence, Rhode Island
Miami, Florida
Indianapolis, Indiana
Detroit, Michigan
Albuquerque, New Mexico



Upper Valley, New Hampshire
Phoenix, Arizona
Daytona Beach, Florida
Hartford, Connecticut
Des Moines, Iowa
Philadelphia, Pennsylvania
Las Vegas, Nevada
Eugene, Oregon
Sacramento, California
Billings, Montana
San Antonio, Texas
Fargo, North Dakota
New York, New York
Lexington, Kentucky
Little Rock, Arkansas
Cincinnati, Ohio
Sioux Falls, South Dakota
Salt Lake City, Utah

SESSION FINDINGS

Standard Polling Questions

This meeting followed a unique format, but began with a few questions used at all community meetings. Virtually all attendees believed that the U.S. health care system is in either a state of crisis (58 percent) or has major problems (40 percent). Two thirds voted that the principal reason to have health insurance is to protect against high health care costs while one third chose paying for everyday medical expenses. Almost everyone attending (98 percent) agreed with the sentiment that it should be public policy that all Americans have affordable health care coverage.

While “trade-offs” were not explicitly addressed at this meeting, the moderator polled the audience on whether it should be a priority for public health care spending that coverage for certain end-of life care services of questionable value be limited in order to provide more at-home care and comfort care for the dying. Sixty percent of attendees strongly agreed with this statement and 30 percent agreed. Five percent strongly disagreed.

Hopes, Fears and Challenges

Care has to be taken out of the medical system and accommodate what happens in the community.

Shift resources out of intensive care to family/community care. It's way out of balance.

This session began with participants generating a list of concerns that they considered important at the end of life. This list was a combination of items suggested by the moderator that have appeared in surveys used elsewhere in the country and items suggested by attendees. The list was then divided into services which were strictly medical and those which were not. The first discussion focused on non-medical issues which included: continence/incontinence, emotional well-being, transportation, personal care, meals and cooking, choice, meaningful closure, being at home, familiar health care professionals, personal dignity, the financial impact of dying on one's family and not dying alone.

People were asked from where they would look for assistance with these concerns: family and friends, family and friends with paid assistance, paid assistance only or volunteers from the community. For virtually all of these important aspects of life, the audience agreed that the primary source of support was family and friends, but there was a strong sentiment that paid assistance should be available particularly for incontinence issues, transportation, homemaking and housekeeping and assistance in staying at home. Participants desired respite services for the primary care provider and a contact person for coordination of community help. When asked what they thought of the overall list of concerns, a majority of participants thought it was good but incomplete.

When asked about their greatest fears, the audience generated their own lists of key concerns and identified intractable pain as what they most feared, followed closely by losing control and prolongation of death. Dying alone, unresolved issues, family suffering and losing the ability to think were other fears. They identified their greatest challenge as graceful surrender (26 percent), followed by getting the system to work for you and “maintaining choice and having it honored.”

Support from the Medical System

Participants generated a long list of potential supports one could receive from the medical system. Support was strongest for “honoring my choices,” followed closely by “making sure I am not in too much pain,” “making sure doctors and nurses are fully informed, so they can inform patients,” “knowing when it is time to provide palliative care,” “timely hospice referrals” and “honest communications.” Support was low for “praying with me,” “keeping me alive” and “delivering cutting edge care.” There was some support for assisted suicide.

Support from Others

Attendees generated a list of practical suggestions for support they would like from other people which included: listening in a non-judgmental way, offering specific help, respect for privacy, respite for the primary care provider, identification of contact person for coordinating community help, financial assistance for minor problems, more responsiveness from employers and “having some fun.”

Where to spend one’s Last Days

Deliver us from the medical system.

The majority of attendees (69 percent) would like to spend their last days of life at home. Nineteen percent opted for a hospice facility. Most people thought this choice important, but would find another location acceptable if aspects of the experience were well settled.

Advice to Policymakers

Care should not be compromised by ability to pay.

There is a core need to support family care givers.

Everyone in, no one out. No cherry-picking.

As a health care consumer, I want appropriate, timely, comprehensive care from conception to death and I would be willing to pay a modest percentage of income across my working life to achieve this.

Participants were asked what advice they would give their Senators or, this being New Hampshire, a presidential candidate on “living well through the end of life.” Initial comments focused on the need for a system of care that supports family and is based in the community, not medical institutions. One participant reminded others that care givers are very low paid. There was a call for realigning payment incentives to emphasize talk over procedures. There was also a call to revisit Medicare payment rules for hospice.

The discussion soon turned to broader issues. Participants were quick to note that “all Americans need access to health care across all ages” and some expressed support for a single payer system. As at the other community meetings which had a more general focus, participants voiced support for a stronger emphasis on prevention and asked that care decisions be taken out of the hands of insurance companies.

METHODOLOGY

Participants at the meeting sat at tables of eight to ten people, each with a volunteer facilitator. As noted above, the meeting began with a presentation by Dr. Ira Byock, who also facilitated the meeting. The meeting format called for table-level discussions, reporting table findings to the full group, quick surveys of the full group and interactions at the table and full group levels. Key points raised to the full group were displayed on a screen. Participants answered questions using key pads and results were displayed as received. Findings from these instant polls formed the basis for full group discussion. This meeting was two and a half hours in length, shorter than most Working Group Community Meetings, and, unlike most meetings, focused on a single topic. Complete polling data from this meeting is available at www.citizenshealthcare.gov.

PARTICIPATION

The Citizens' Health Care Working Group Upper Valley New Hampshire Community Meeting was held March 31, 2006 from 4:00 to 6:30 p.m. at Alumni Hall, Dartmouth College in Hanover, New Hampshire with approximately 120 in attendance. Dotty Bazos represented the Working Group at the meeting and was interviewed on Vermont Public Radio the morning of the meeting. The event was facilitated by Dr. Ira Byock. Contributing to the meeting's success were: the Community Health Institute/JSI, Dartmouth-Hitchcock Medical Center, the Center for Evaluative and Clinical Sciences and the New Hampshire Hospice and Palliative Care Organization.

The audience attending the Upper Valley meeting had many of the characteristics of the audiences of other community meetings: the typical attendee was female (68 percent); between the ages of 45 and 64 (57 percent) and well-educated (24 percent with a bachelor's degree, 67 percent with a graduate or professional degree). Not surprisingly, a large proportion of attendees—29 percent—was 65 years of age or older. Sixty-five percent had employer-sponsored insurance; 22 percent were on Medicare. Sixty-five percent were either employed working full time or self-employed; 27 percent listed "Other" as their employment status.

STAYING INVOLVED

Through the Citizens' Health Care Working Group website, we have made it possible for you to stay involved in the discussion – and to encourage others to get involved as well. Visit the website at www.citizenshealthcare.gov and:

- Download a **Community Meeting Kit** to plan a meeting for your family, friends, neighbors and co-workers.
www.citizenshealthcare.gov/community/mtg_kit.php
- Find a list of other cities hosting meetings and spread the word to friends and family in those cities to **Register for a Community Meeting** near them.
www.citizenshealthcare.gov/register
- Add your opinions to three different polls in the **Public Comment Center**
www.citizenshealthcare.gov/speak_out/comment.php
- Read what members of the Working Group and other Americans have to say by following the link on the homepage to the **Citizens' Blogs**.
www.citizenshealthcare.gov
- Share your opinions on the future of health care by creating your own blog by following the link on the homepage to the **Citizens' Blogs**.
www.citizenshealthcare.gov
- Join a growing group of individuals engaging in back-and-forth discussions on the **Discussion Forums** by following the link on the homepage.
www.citizenshealthcare.gov
- Read **Community Meeting Reports** from other cities to see how opinions are shaping up across the country.
www.citizenshealthcare.gov/community/mtng_files/complete.php
- Stay tuned to the homepage for the Citizens' Health Care Working Group **Preliminary Recommendations** (available in early June) and get involved in the 90-day public comment period.
www.citizenshealthcare.gov
- Stay tuned to the homepage for information on the **Final Recommendations** and the schedule of **Congressional hearings** to address those recommendations.
www.citizenshealthcare.gov

If you have additional ideas on how to get others involved, we would love to hear them. Please contact Jessica Federer at 301-443-1521 or jessica.federer@ahrq.hhs.gov.

DATA

Percent A
Are you male or female?

31.60%	1	Male
68.40%	2	Female

Percent B
How old are you?

1.10%	1	Under 25
12.80%	2	25 to 44
57.40%	3	45 to 64
28.70%	4	Over 65

Percent C
Are you Hispanic or Latino?

1.10%	1	Yes
95.80%	2	No
3.20%	3	No Response

Percent D
Which of these groups best represents your race?

91.40%	1	White
4.30%	2	Black or African American
0.00%	3	Asian
0.00%	4	Native Hawaiian or Pacific Islander
0.00%	5	American Indian or Alaska Native
0.00%	6	Other
4.30%	7	Decline to answer

Percent E
What is the highest grade or year of school you completed?

1.10%	1	Elementary (grades 1 to 8)
0.00%	2	Some high school
1.10%	3	High school graduate or GED
4.30%	4	Some college
2.20%	5	Associate Degree
23.90%	6	Bachelor's Degree
67.40%	7	Graduate or professional degree
0.00%	8	Decline to answer

Percent F
What is your primary source of health care coverage?

64.60%	1	Employer-based insurance
9.40%	2	Self-purchased insurance
1.00%	3	Veterans'
21.90%	4	Medicare
0.00%	5	Medicaid
3.10%	6	Other
0.00%	7	None

0.00% 8 Not sure

Percent G

What is your employment status?

14.70%	1	Self-employed
41.10%	2	Employed - working full time
8.40%	3	Employed - working part-time
1.10%	4	Not employed / currently looking for work
7.40%	5	Homemaker
27.40%	6	Other

Percent H

Which one of these statements do you think best describes the U.S. health care system today?

58.10%	1	It is in a state of crisis
39.80%	2	It has major problems
1.10%	3	It has minor problems
0.00%	4	It does not have any problems
1.10%	5	No opinion

Percent I

Which one of the following do you think is the MOST important reason to have health insurance?

32.30%	1	To pay for everyday medical expenses
67.70%	2	To protect against high medical costs
0.00%	3	No opinion

Percent J

Should it be public policy that all Americans have affordable health care coverage? [By public policy we mean that the stated public goal is set out in federal or state law.]

97.90%	1	Yes
2.10%	2	No

Percent K

Limiting coverage for certain end-of-life care services of questionable value in order to provide more at-home and comfort care for the dying should be an important priority for public spending on health and health care in America.

59.80%	1	Strongly agree
29.90%	2	Agree
2.40%	3	No opinion
3.40%	4	Disagree
4.60%	5	Strongly disagree

What is most important to you?

Percent L

A - Elimination (Contentence or incontentence of bowel bladder)

3.50% Family and friends

81.40% Family and friends with paid assistance
12.80% Paid assistance only
2.30% Volunteer from the community

B - Emotional well-being

57.10% Family and friends
42.90% Family and friends with paid assistance
0.00% Paid assistance only
0.00% Volunteer from the community

C - How I look - appearance

54.90% Family and friends
39.40% Family and friends with paid assistance
2.80% Paid assistance only
2.80% Volunteer from the community

D - Transportation

34.60% Family and friends
46.90% Family and friends with paid assistance
3.70% Paid assistance only
14.80% Volunteer from the community

E - Personal care like dressing or grooming (meals and cooking, homemaking)

23.90% Family and friends
72.70% Family and friends with paid assistance
3.40% Paid assistance only
0.00% Volunteer from the community

F - Meals and cooking

36.30% Family and friends
53.80% Family and friends with paid assistance
3.80% Paid assistance only
6.30% Volunteer from the community

G - Homemaking or housekeeping

12.50% Family and friends
60.90% Family and friends with paid assistance
25.00% Paid assistance only
1.60% Volunteer from the community

H - A respect of self as primary responsibility

76.30% Family and friends
17.50% Family and friends with paid assistance
3.80% Paid assistance only
2.50% Volunteer from the community

I - Compassionate involvement from support givers

41.80% Family and friends
57.00% Family and friends with paid assistance
1.30% Paid assistance only

0.00% Volunteer from the community

J - Meaningful closure

64.30% Family and friends
27.40% Family and friends with paid assistance
1.20% Paid assistance only
7.10% Volunteer from the community

K - Choice, being in control (reconciling desires)

58.70% Family and friends
37.30% Family and friends with paid assistance
2.70% Paid assistance only
1.30% Volunteer from the community

L - Being at home

15.20% Family and friends
82.30% Family and friends with paid assistance
2.50% Paid assistance only
0.00% Volunteer from the community

M - Being able to communicate, clear-headed at the end

35.10% Family and friends
61.00% Family and friends with paid assistance
3.90% Paid assistance only
0.00% Volunteer from the community

N - Dignity

41.90% Family and friends
53.50% Family and friends with paid assistance
3.50% Paid assistance only
1.20% Volunteer from the community

O - An advocate

43.00% Family and friends
48.80% Family and friends with paid assistance
1.20% Paid assistance only
7.00% Volunteer from the community

P - Not dying alone

62.50% Family and friends
34.10% Family and friends with paid assistance
2.30% Paid assistance only
1.10% Volunteer from the community

Percent M

Which one of the following do you think is the MOST important reason to have health insurance?

36.90% 1 To pay for everyday medical expenses
58.50% 2 To protect against high medical costs
4.60% 3 No opinion

Percent	N	
What is your greatest fear?		
18.10%	1	Losing control
21.70%	2	Intractible pain
4.80%	3	Not having durable power of attorney voice heard
9.60%	4	Dying alone
7.20%	5	Losing dignity
8.40%	6	Unresolved issues
6.00%	7	Loss of ability to think
6.00%	8	Family suffering
18.10%	9	Prolongation of death
0.00%	10	Not being at home

Percent	O	
What is your greatest challenge?		
5.90%	1	Being let go of (by people around you)
16.50%	2	Getting the system to work for you
25.90%	3	Graceful surrender
15.30%	4	Maintaining choice and having it honored
8.20%	5	Choosing whether to end one's own life
3.50%	6	Maintaining, and access to dignity
10.60%	7	Being able to afford care
5.90%	8	Accepting help
2.40%	9	Good pain relief
5.90%	10	Remaining cheerful

Rank	P	
How much do you agree or disagree with each approach? (1=agree strongly, 5=disagree strongly)		
20th	3.62	A - Delivering cutting-edge life-saving care
21st	3.83	B - Keeping me alive
1st	1.10	C - Honoring my choices
6th	1.23	D - Making sure I am not in too much pain
10th	1.43	E - Making sure I do not suffer
2nd	1.18	F - Respecting my dignity
15th	2.26	G - Taking care of my family
19th	3.43	H - Keeping me company
22nd	4.20	I - Praying with me
4th	1.22	J - Having the doctors and nurses fully informed, so they can inform patients
9th	1.31	K - Continuity of care; no abandonment
12th	1.55	L - Assisting with decisions true to values
5th	1.23	M - Knowing when it is time to provide palliative care
13th	1.85	N - Having needed services paid for
16th	2.26	O - Assisted suicide
8th	1.30	P - Smooth transitions to curative interventions to care
11th	1.48	Q - Clarity around the billing process
14th	1.89	R - One person coordinating care
7th	1.25	S - Timely hospice referrals
3rd	1.21	T - Honest communications

- 17th 2.40 U - Limited number of care providers
- 18th 2.67 V- Euthanasia

Q

How could other people best support you and your ill loved one?

- 1 Support for spouse and family during and after
- 2 People listening in an non-judgemental fashion
- 3 Identify contact person for coordination of community help
- 4 Offering specific help
- 5 Provide respite for primary caregiver
- 6 Have employers be more responsive to family problems
- 7 Implementing "211" information dialing services
- 8 Having some fun
- 9 Financial support for minor problems (e.g. broken glasses)
- 10 Knowledgeable gatekeeper / privacy
- 11 Community "delivering us" from medical system

Percent R

Where would you want to spend the last days of your life?

- 69.20% 1 Home
- 6.40% 2 Home of family or friend
- 0.00% 3 Nursing home
- 1.30% 4 Hospital
- 3.80% 5 Other
- 19.20% 6 Hospice facility

Percent S

How important is it to you that you spend the last days of your life in the place that you chose in the question above?

- 16.90% 1 Extremely important
- 71.10% 2 Important
- 12.00% 3 Not important to me at all

Percent T

If all other aspects of the experience were well settled (pain was managed, financial issues addressed, and family well-supported) would it be acceptable for you to be in a different place than the place you just chose?

- 84.40% 1 Acceptable
- 15.60% 2 Not acceptable